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Social Role Functioning in Parkinson's disease: A mixed-methods systematic review

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Abstract

Objectives: Parkinson's disease (PD) is a progressive neurodegenerative disease that often impedes activities of daily living (ADL) and social functioning. Impairment in these areas can alter social roles by interfering with employment status, household management, friendships and other relationships. Understanding how PD affects social functioning can help clinicians choose management strategies that mitigate these changes.

Methods: We conducted a mixed-methods systematic review of existing literature on social roles and social functioning in PD. A tailored search strategy in 5 databases identified 51 full-text reports that fulfilled the inclusion criteria and passed the quality appraisal. We aggregated and analyzed the results from these studies and then created a narrative summary.

Results: Our review demonstrates how PD causes many people to withdraw from their accustomed social roles and experience deficits in corresponding activities. We describe how PD symptoms (e.g. tremor, facial masking, neuropsychiatric symptoms) interfere with relationships (e.g. couple, friends, family) and precipitate earlier departure from the workforce. Additionally,

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several studies demonstrated that conventional PD therapy has little positive effect on social role functioning.

Conclusions: Our report presents critical insight into how PD affects social functioning and gives direction to future studies and interventions (e.g. couple counseling, recreational activities).

Keywords

Parkinson's disease; quality of life; social roles; caregiver

1. Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disease characterized by motor and non-motor symptoms that impair functioning in activities of daily living (ADL) and cause changes in social functioning^{1,2}. Social functioning encompasses performance in specific social roles, or "expected ways of behaving," which are established by both an individual's personal goals and societal norms³. In chronic illnesses, symptoms impact the ability to fulfill social roles such as employment, household management, friendships, and other relationships⁴. Changes in social role functioning are particularly troublesome because satisfaction with social role performance is related to overall happiness and quality of life⁵. Additionally, social isolation and loneliness is a risk factor for depression, cognitive decline, increased health care costs, and overall mortality⁶⁻⁹.

Quality of life (QoL) has become a frequent outcome of interest in clinical trials and is one of the most important factors for determining clinical care for people with chronic diseases^{10,11}. In the PD field, research on quality of life has increased and several systematic reviews describe the determinants of quality of life, economic impact of decreased quality of life in PD, how to measure quality of life, and prognostic factors related to QoL¹²⁻¹⁵. Van Uem et al. recently published a review on health-related quality of life in patients with PD using the International Classification of Functioning, Disability, and Health (ICF) developed by the World Health Organization as a framework. The ICF model was designed to represent health and disability at individual and population levels, using the following domains: body functions and structures, activities of daily living, participation in social roles, personal features, and environmental factors¹⁶. This review found that poor health-related quality of life was most strongly associated with social role functioning; however, there is a significant dearth of research conducted in this area compared to the other domains¹⁷. Because no review has examined specific aspects of social functioning in PD, we conducted a mixed methods systematic review, incorporating studies estimating the association of social function with PD employing statistical methods and qualitative studies seeking to understand the construct of social functioning in PD. Because no review has examined specific aspects of social functioning in PD, we conducted a mixed-methods systematic review. We aim to describe what is currently known about social role functioning in PD.

2. Methods

2.1 Search strategy and study selection

A literature search was performed in March 2018, using several MeSH terms related to social roles (Supplementary Table 1). All articles published before March 1, 2018 were included in the search, yielding 7129 articles from Pubmed (2257), Embase (3300), PsychINFO (1078), CINAHL (373) and Cochrane (121). After removing duplicates (n=1872), the titles and abstracts of the remaining 5257 articles were screened by two reviewers (JH, KP). Inclusion criteria for the full-text screening were: (1) Parkinson's disease participants and (2) at least one outcome of the paper focused on social functioning or a social role. Articles were excluded from the review if they were not available in English or if they did not present original research. In order to provide the most comprehensive review of papers investigating social functioning we included studies employing a variety of instruments and data collection methods; due to the heterogeneity of instruments used we were unable to conduct a meta-analysis. However, as the first review conducted on a rarely studied area in PD, we believe that a review including quantitative and qualitative studies with a narrative summary of the results was most appropriate.

After the initial screening, 4843 articles were excluded, leaving 414 articles in the full text evaluation (Figure 1). The full texts were then read to confirm they met inclusion criteria. A third reviewer (MS) served as an adjudicator when there was disagreement about inclusion in the full-text evaluation. After full text review, 344 articles were excluded, leaving 70 articles for quality appraisal and data extraction. We also searched the reference sections of the articles that were included after full-text review for any additional papers that may have been missed in the database search (2 additional articles were identified).

2.2 Data extraction and quality appraisal of included studies

One reviewer (KP) used a quality appraisal checklist to independently evaluate the quality of the 70 articles remaining after the full-text assessment. We used the Critical Appraisal of Programme checklist for the quality appraisal¹⁸. The checklist type was selected based on the study design. The appraisal resulted in the inclusion of 51 articles and the exclusion of 19 articles after the quality appraisal. One reviewer (KP) extracted data from the 51 articles that remained after the quality appraisal. Articles were then divided based on the type of analysis used – quantitative or qualitative.

2.3 Data Synthesis

Our mixed-methods methodology facilitated a synthesis of published results and enabled us to produce a narrative summary of existing work. Using the Cochrane procedure for narrative summary, one reviewer (KP) read through each paper and first developed a preliminary composition of the results (Supplementary Tables 2– 7)¹⁹. A combination of inductive and deductive reasoning was applied for the analysis. We employed deductive synthesis to first divide articles based on the type of social role described: couple relationship, parent/family role, work role, friendship role, social/leisure role or grouped into a general social functioning category if no specific role was described. Some papers discussed multiple roles; the information relevant to each role was extracted from the paper

and categorized in the appropriate section. Then, within each group, we applied an inductive synthesis to identify patterns of topics discussed and further divide papers into a sub-theme. The data from studies were then translated using thematic analysis to describe common conclusions across different papers (within the previously defined social roles) (Table 1).

3. Results

We identified 51 papers to include in our analysis, all published between 1973 and 2018. Of these, 23 papers employed primarily quantitative methods, 23 were qualitative, and 4 used a mixed-methods approach. Most study designs were cross-sectional (n=44) and the remaining articles were longitudinal (n=7). The papers included in this review either covered general social functioning (n=30) or discussed a specific social role, including the couple relationship (n=36), parent/family role (n=14), friendship role (n=9), work role (n=19), and/or social/leisure role (n=6) (Figure 2).

3.1 Quantitative Studies: Instruments

A wide variety of instruments were used to measure social role functioning. Some studies included full questionnaires such as the Marital Adjustment Test. Other studies included questionnaires that assessed social functioning in a subsection of the full scale, for example the Nottingham Health Profile.

3.2 Qualitative Studies: Data collection methods

All of the qualitative studies employed in-depth interviews as the main data collection method. Questions that were included in the interviews were generally open-ended (e.g. “Can you tell me what your life is like with Parkinson’s disease?”), some focused on specific social roles (e.g. “Can you describe how the disease has affected your relationship with family, friends, and your community?”), while others were broad (e.g. “How has your ‘usual state of health’ changed after diagnosis?”).

3.4 Narrative analysis of papers by social role category

3.4.1 General social functioning—General social functioning included papers (n=30) that described overall socialization or social functioning but didn’t discuss a specific social role. These articles were categorized into three sub-themes - clinical observations/PD symptoms (n=3), treatment/intervention effect (n= 9), and quality of life/life changes after PD (n=4). The quantitative study described that facial masking was associated with social functioning problems such as social rejection, although this finding was attenuated after controlling for depression ²⁰. The qualitative studies described how communication problems (i.e. voice problems) were associated with changes in socialization such as social withdrawal ²¹. People living with Parkinson’s felt that PD restricted their activity, decreased their socialization, and limited their ability to have a “meaningful” social contribution ^{21–23}. Papers describing treatments and interventions for improving Parkinson’s symptoms included “typical” PD treatments (i.e. medication and deep brain stimulation (DBS) surgery), exercise interventions (e.g. tango class), and educational programs (e.g. psychoeducation). Quantitative studies describing DBS and levodopa frequently reported no change in social functioning following surgery or in some cases a detrimental change ^{24–26}.

It is unclear why social functioning inconsistently improves post-DBS; however, a qualitative study revealed that expectations of surgery outcomes influenced relationships (couple and work) after surgery (see corresponding sections for more details)²⁷. A psychoeducation class for DBS participants was found to significantly improve postsurgical social adjustment²⁸. The Stanford Chronic Disease Self-Management Program, which aimed to improve social functioning, did not significantly improve social support scores, however, there were some positive correlations between changes in social support and changes in self-management outcomes after program participation²⁹.

Another class of PD therapy was behavioral interventions, including a dance class, a support group, and a self-management training program. These interventions had a positive effect on social functioning, by increasing social engagement directly through the activity²⁹⁻³⁴. Papers describing quality of life or life changes after PD found that cognitive functioning related to participation^{35,36}. Additionally, Farhadi et al. found that females reported worse psychosocial functioning and social support³⁷.

3.4.2 Couple Relationship—The couple relationship has been measured by concordance with partner, dependence on partner, feelings about partner, relationship satisfaction, and sexual adjustment (i.e. frequency and enjoyment of intercourse)³⁸. Articles discussing this social role focused on the effect of clinical/PD symptoms (n=7), relationship satisfaction (nonsexual) (n=6), sexual satisfaction (n=5), and the effect of treatment (n=5). The quantitative papers that described clinical/PD symptoms affecting the couple relationship reported that facial masking and Hoehn & Yahr stage were correlated to an impaired couple relationship, while speech problems had no significant impact (20,43). Older couples and those who were able to better cope with the disease reported better relationships³⁹. The qualitative studies revealed positive and negative impacts on the couple relationship. A positive change people living with Parkinson's and their spouses reported was the affirmation of their commitment to each other after the diagnosis^{41,42}. Some negative changes reported included shifting relational roles (with more responsibility falling on the care partner changes in sexual intimacy, engaging in fewer activities together, and financial burden⁴¹⁻⁴⁵. Ten papers described the impact of PD on non-sexual aspects (e.g. communication, attention, shared activities) of relationship satisfaction. Buhmann et al found that people living with Parkinson's, especially women, believed these non-sexual aspects of their relationship became more important after PD diagnosis⁴⁶. Eleanor Singer compared marriage satisfaction between people living with Parkinson's and age-matched controls and found no significant difference⁴⁷. Three studies found that depression, anxiety, negative social exchanges, and alexithymia were associated with reduced relationship satisfaction⁴⁸⁻⁵⁰. Mavandadi et al. measured relationship satisfaction from the care partner perspective and found that satisfaction was related to the care partner's "benefit finding", or ability to experience positive change when faced with a stressor like PD⁵⁰. Karlstedt et al. investigated relationship mutuality, "the positive quality of a relationship", and found that having a male care partner was associated with higher mutuality score for the people living with Parkinson's. Care partner mutuality score was associated with the people living with Parkinson's mutuality score and the people living with Parkinson's cognitive ability⁵¹. Qualitative papers in this sub-theme reported that uncertainty about the future and role

changes that placed a greater burden on the care partner were strongly associated with relationship quality^{41,43,52}. Five papers described sexual functioning in PD and how it affects the couple relationship. Lower sexual satisfaction was more common among younger-onset people living with Parkinson's, males, and those with worse motor scores (MDS-UPDRS), fatigue, and rigidity^{53,54}. Papers also reported that sex life satisfaction was significantly associated with marital satisfaction^{48,55}. Fleming et al. elucidated this issue, listing dramatic increases or decreases in libido, as well as a shift in relationship roles from partner to carer to be the main reasons for sex life dissatisfaction⁴¹. Five papers described how different interventions or therapies impacted the couple relationship. DBS was found to diminish sexual desire and, in some cases, worsen marital satisfaction^{26,47,56}. Agid et al. provided an explanation for this worsened marital quality following surgery: either people living with Parkinson's rejected their spouse after they felt "cured" or they were rejected by their spouse who expected them to be able to return to their pre-morbid level of functioning following surgery²⁶. Similarly, higher doses of levodopa were associated with more frequent thoughts about breaking up with a partner and with relationship termination⁴⁶. However, support group attendance had a positive influence on the relationship by providing a way for couples to have a shared social activity⁵⁷.

3.4.3 Family Role—The family role has been defined by feelings about family interactions, the ability to handle family financial needs, the frequency and quality of interactions with family members, interest in a child's activities and quality of interaction with children³⁸. Two mixed-methods papers described how treatments/interventions influenced the family relationship^{27,31}. People living with Parkinson's who participated in a tango intervention reported improved family role functioning after the classes³¹. Schüpbach et al. reported improved family relationships after DBS surgery were more common than strained relationships²⁷. Another common theme related to the family role was discussing or sharing the disease with family members. Five papers described that communication early in the disease was crucial for facilitating understanding of the disease among family members and reducing its burden^{39,41,54,58,59}. Fleming et al. provided more information about why communication was a struggle for some people living with Parkinson's. People living with Parkinson's reported the need to "protect" their families and did not want their children to "miss out" on anything because of the diagnosis⁴¹. Navarta-Sanchez described how health care providers and family members influenced the way people living with Parkinson's handled their disease³⁹. Receiving support from their family helped make people living with Parkinson's feel more secure and motivated to maintain their treatment regimen³⁹.

Four papers described family relationship satisfaction in PD. A quantitative study comparing people living with Parkinson's to age-matched controls found no difference in parental role satisfaction²⁴. There were three qualitative papers that discussed the importance of family relationships for QoL in people living with Parkinson's^{23,42,60}. Additionally, for some people living with Parkinson's who were unable to work, parenting or family relationships became a higher priority.

3.4.4 Friendship Role—The friendship role has been measured by how frequently contact (e.g. telephone, email, in person) is initiated with friends and the quality of these interactions³⁸. Most people living with Parkinson's reported the number of social contacts they had remained stable after diagnosis and following some treatments for PD (e.g. DBS surgery)^{4,56,61,62}. Rubenstein et al. noted that although the number of visits friends made to people living with Parkinson's remained the same, people living with Parkinson's were less likely to initiate social outings with friends⁶¹. Soleimani et al. revealed that people living with Parkinson's were concerned about losing social connectedness because of their disease (preventing them from leaving the house or increasing their desire to remain isolated to conceal symptoms)⁶². Reduced social outings were found to greatly influence QoL as well as functioning in other relationships (e.g. couple, family)^{23,63}. Fleming et al. (2004) reported a divide in how friendships changed with PD. Some friendships were strengthened while others ended⁴¹. There was no consensus on factors that predicted relationship outcome following diagnosis.

3.4.5 Work Role—The work role has previously been measured by incorporating both paid and unpaid work (e.g. house work). Work role is defined by the duration of work, any changes to employment (e.g. full-time to part-time), respondent's feelings about the quality of their work, and relationships with co-workers³⁸. Nineteen papers described the work role and how it was impaired by PD. Three quantitative papers found factors that contributed to leaving the workforce included anxiety, older age, longer disease duration, female sex, cognitive performance, depression, and ability to perform ADL (e.g. dressing, hygiene)^{36,64,65}. Several papers described that people living with Parkinson's decreased their work outside of the home and at home. Decreased employment was more evident in the young-onset group, with reasons for leaving the workforce often tied to the inability to meet job demands^{42,43,54,56,61,66,67}. Habermann (1996) reported that people living with Parkinson's who remained in the workforce described goal adjustment, e.g., changing their focus from career advancement to maintaining their current position⁴³. Qualitative studies also revealed that leaving the workforce impacted other social roles and overall QoL due to perceived loss of societal contribution and social contacts from work^{23,52,62}. Two papers described the impact of DBS and levodopa on work roles. There was no evidence that levodopa led people to rejoin the workforce²⁴. Professional activity following DBS was more often worsened than improved²⁷.

3.4.6 Social and Leisure Role—The social and leisure role has been measured by the frequency, duration and quality of social activities (e.g. hobbies, membership in organizations)³⁸. Four papers described that the types of activities in which people living with Parkinson's engaged tended to be more solitary and sedentary, such as reading or watching TV^{4,24,41,68}. Two qualitative papers provided reasons for this shift to more sedentary activities, including people living with Parkinson's giving up more physically demanding hobbies because of the disease or favoring more solitary activities because of the unpredictability of symptoms and embarrassment about symptoms^{41,68}. People living with Parkinson's mentioned that planning ahead was crucial for maintaining social activities and navigating symptom demands⁶⁸. Six papers described the impact of treatment/interventions on social activities. Social and leisure role performance was improved for people living with

Parkinson's who participated in activities with other people living with Parkinson's (e.g. tango class) (73). These classes naturally provided an opportunity for socialization, as well as the ability to meet with people with similar challenges. Two papers evaluated the effect of DBS on social and leisure roles. Boel et al. described no change in membership to organizations following DBS⁵⁶. Liddle et al. found that people living with Parkinson's reported improved leisure performance after DBS⁷¹.

4. Discussion

4.1 Summary of findings

The aim of this review was to describe the effect of PD on social role functioning. Our work integrates research on how PD affects various social roles, including the couple relationship, family, friendship, work, and social/leisure roles. Our analysis uncovered three central findings: (1) PD can affect performance in different social roles or may cause withdrawal from these roles; (2) standard pharmacologic and surgical interventions have little positive effect on social role functioning in PD; and (3) a wide variety of instruments and data collection methods were used in the reviewed studies, demonstrating a pressing need for a more uniform method to evaluate social role functioning in PD. The primary focus of this review was on the patient related factors that are associated with social functioning. However, the patient's functioning is also dependent on how partners or caregivers cope with the disease of their loved one and the extent to which this influences their own lives. Some studies focusing on this issue have been published, but we considered caregiver outcomes to be beyond the scope of this review^{72,73}.

4.2 Strengths and limitations

Our systematic review is the first to summarize social functioning in PD, using a mixed-methods approach. We applied Cochrane's robust methodological procedures during the review process and had more than one reviewer at each stage to reduce bias. We also acknowledge that we could have missed some potentially relevant articles in other databases or the grey literature. However, we do feel that the five databases we have selected provide relevant sources for papers that would be included in our review.

Furthermore, our review only addressed social functioning from the perspective of the person with Parkinson's disease. Social functioning is important to study in a network sense as well because it is a group concept and an individual concept. However, the focus of our review was to describe the impact of Parkinson's disease on the person with Parkinson's disease and therefore we restricted our inclusion criteria to focus on this topic. We feel that another review would better tackle the caregiver side of the equation.

4.3 Implications for research, policy, and practice

Social role performance is a priority for people with chronic diseases and the clinicians who treat them. Hammarlund et al. researched which outcome measures were most important in PD trials from the perspectives of healthcare professionals and people living with Parkinson's⁷⁴. Study participants (people living with Parkinson's and health care professionals) most frequently ranked aspects related to social involvement (i.e. quality of

life, control of disease processes, ability to be on visiting terms, socializing, and participating in society) as the most important outcome. Additionally, the WHO emphasizes participation in social roles and social role performance among people with chronic disease or disability as a crucial method in which to prevent physical and mental health problems¹⁶. Our review demonstrates that social functioning is an expanding area of research in clinical practice. Although some papers were published in more academic research-oriented journals (n=20), there were several papers in neurology journals (n=8), nursing journals (n=7) and rehabilitation journals (n=12), and occupational therapy journals (n=4). Additionally, publications related to social functioning have been increasing in popularity, with most of the papers included in this review published in the last 4 years.

Our review identified several correlates of impaired social role performance in PD, including disease severity, anxiety, depression, and cognitive impairment. However, less attention has been paid to interventions or methods of preserving or improving social role functioning. In fact, standard therapies for the motor symptoms of Parkinson's disease (DBS and levodopa) have not been shown to reliably improve social functioning and in some cases even worsen social role performance. Therefore, other approaches, such as non-pharmacologic therapies, should be investigated. A few studies found that activities like dancing or support groups improved social role functioning and quality of life^{31,32,43,75}. Future research should focus on a broader range of interventions to improve social role functioning in PD.

This review provides several targets related to social role functioning, which could be used to develop interventions. Poor general social functioning was associated with drooling, facial masking, communication problems, and cognitive impairment^{20,21,30,35,76-80}. Impaired couple relationships were related to facial masking, higher Hoehn and Yahr stage, lack of coping responses (i.e. spouse "benefit finding"), and sexual dysfunction^{20,39,40}. Earlier departure from the workforce was associated with female sex, older age, longer disease duration, anxiety, ADL performance, depression, and cognitive impairment^{33,42,54,56,61,66,67}. The breadth of factors that contribute to impaired functioning signals a variety of plausible intervention targets. Although some factors are fixed, such as sex, age of onset, disease duration, age, and disease severity, there are many that can be targeted with treatment, including neuropsychiatric symptoms, sexual dysfunction, and motor function. Additionally, fixed factors can serve as markers to identify people living with Parkinson's at greater risk problems in social role functioning. Certain current interventions and treatments address some of the modifiable factors associated with impaired social functioning. A variety of medications, therapies, and complementary strategies exist to address the neuropsychiatric and motor symptoms in PD. However, research on how these approaches affect social functioning is limited. Additionally, treatments for modifiable symptoms, such as sexual dysfunction, have been less thoroughly explored despite the strong association with QoL in many patients with chronic diseases and the couple relationship in PD⁸¹. One review of managing sexual dysfunction in PD promoted several methods, including discussing sexual function in regular neurologist visits, managing medications with sexual side effects, sexual counseling, and timing medications to improve sexual function⁸². Incorporating these methods into regular care could greatly improve the couple relationship and overall QoL for people living with Parkinson's and their spouses. Additionally, understanding how these treatments affect the couple relationship would be beneficial to

people living with Parkinson's, care partners, and clinicians. Of note, within the couple relationship role dysfunction is not exclusively related to patient variables or patient coping, but also depends on caregiver coping and support. This stresses the importance of involving caregivers in (non-pharmacological) supportive treatments.

Social support is another potential target for interventions to improve social functioning in PD. Previous studies have found that positive affect in PD is increased by the number of social contacts maintained⁸³. Our summary revealed that some friendships are maintained while others are terminated after people living with Parkinson's received their diagnosis⁴¹. However, the friendship role did not have specific factors associated with changes. Future research could further explore if clinical factors can predict changes in these roles. Beyond friendships, this review described activities that provided socialization, resulting in an increase in social support for people living with Parkinson's (e.g. support groups, tango classes). This approach to socialization has been supported in other diseases as well, such as dementia and serious mental illness^{84,85}. Several other exercise classes have been researched in Parkinson's disease, including Tai Chi, boxing, aerobic exercise, and Qigong^{4,63,86,87}. Exercise classes have been shown to improve motor symptoms and QoL; however, direct impact on social functioning requires further investigation. Despite the improvement in health status that social support can provide, many patients view social support utilization as an indicator of functional decline and described actively avoiding the need for social support by adopting behaviors to maintain their independence²⁹. It is important to consider stigma as a potential barrier to participating in interventions to increase social support.

In addition to informing directions for future interventions to improve social role functioning, this review also revealed the lack of PD-specific social functioning measures available to researchers. The quantitative studies included 24 different questionnaires or activities to assess aspects of social role functioning, however, only 3 questionnaires were used in more than one study: the 39-Item Parkinson's Disease Questionnaire (n=3), Social Adjustment Scale (n=2), and Golombok Rust Inventory of Marital State (n=2). The 39-Item Parkinson's Disease Questionnaire is a PD specific questionnaire; however, it does not assess social functioning exclusively and includes only 3 questions that address social function. The Social Adjustment Scale focuses on social roles; however, it is not validated in people living with Parkinson's³⁸. Finally, the Golombok Rust Inventory only measures the couple relationship and has not been validated in PD⁸⁸. There are some factors that could be specific to social functioning in PD (e.g. embarrassment caused by symptoms leading to isolation) that may not be adequately assessed in general questionnaires. A benefit of conducting this mixed-methods review was that the qualitative studies addressed some questions that arose from the quantitative assessments. For example, several studies of DBS revealed that social functioning in the couple relationship was often worsened following surgery; however, family role functioning was improved. This discrepancy could not be clarified by these questionnaires alone, but qualitative interviews uncovered that expectations from patients and spouses play a role in relationship satisfaction following surgery. In order to better measure social role functioning in PD it would be important to develop assessments that are validated in this population and can capture the nuances of the disease that are not currently ascertained from existing questionnaires. Furthermore, new

studies should consider incorporating mixed methods to better understand individual experience with PD.

1. Conclusion

Successful aging involves engagement in social and productive activities⁸⁹. Furthermore, reduced social participation is a risk factor for depression, cognitive decline, increased health care costs, and overall mortality. Our review reveals how PD impairs general social functioning and the ability to fulfill specific roles. A number of symptoms associated with reduced social functioning can be targeted in order to improve function and QoL. However, current PD treatments and interventions have not been shown to adequately improve social functioning. Patients' social participation should be considered as soon as minor losses or changes are detected to prevent isolation and promote successful aging.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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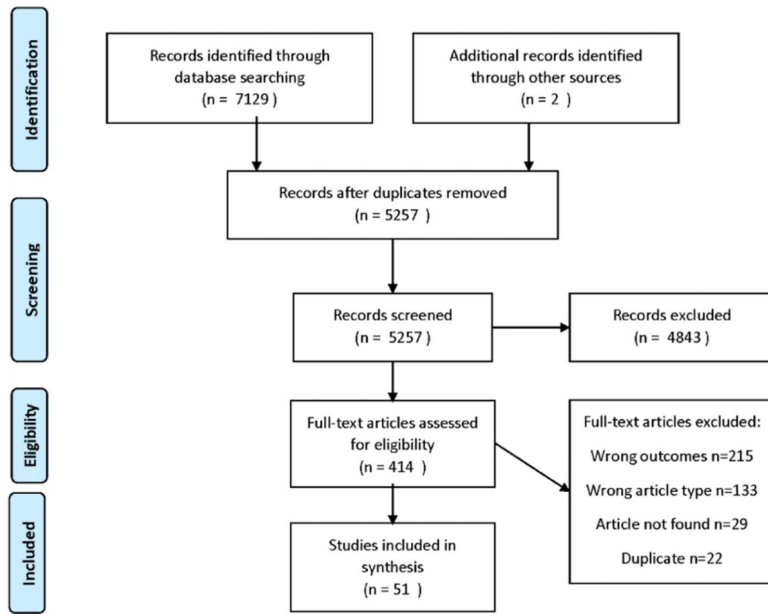


Figure 1. Consort diagram of the review process

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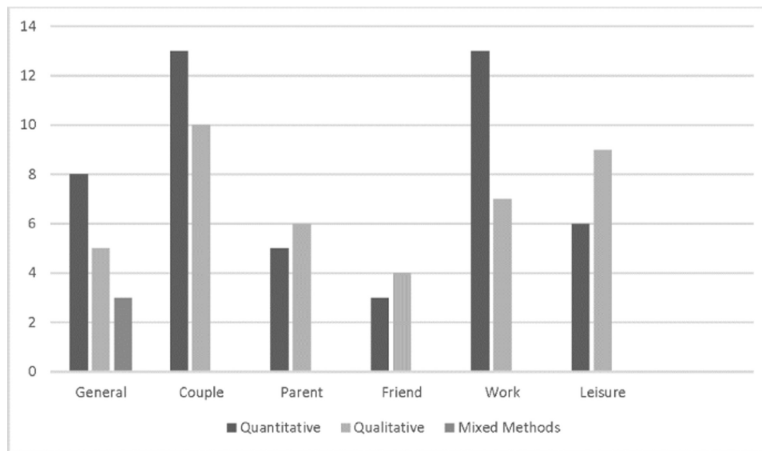


Figure 2.
Distribution of articles based on social role examined and analysis performed

Table 1.

Summary of results from review papers

Social Role	Sub-theme	Summary of results
General Social Functioning	Clinical Observations/PD Symptoms	<ul style="list-style-type: none"> • Facial masking is correlated with social rejection. • Communication problems (e.g. voice problems) can lead to social withdrawal. • PD can limit socialization and ability to feel capable of making a meaningful contribution.
	Treatment/ Intervention Effect	<ul style="list-style-type: none"> • A tango class helped increase social support. • There is little evidence that traditional therapies (medication and DBS) improve social role functioning. • For some people social functioning can decline after DBS surgery, however, psychoeducation can address this decline.
	Quality of Life/ Life Changes after PD	<ul style="list-style-type: none"> • Cognitive functioning is related to social integration. • Females report worse social support than males.
Primary Relationships/ Couple	Clinical/PD symptoms	<ul style="list-style-type: none"> • Facial masking and disease severity were associated with worse partner interaction. • The added responsibility of taking care of a spouse with PD can strain relationships. • Ability to cope with changes predicted psychosocial functioning.
	Relationship Satisfaction (non-sexual aspects)	<ul style="list-style-type: none"> • Non-sexual relationship aspects (e.g. talking, sharing activities) can become more important after PD diagnosis. • Female participants still valued being perceived as a wife & mother. • Greater relationship mutuality predicted better QoL.
	Sexual Satisfaction	<ul style="list-style-type: none"> • Sexual satisfaction was lower for younger onset People with PD. • Sex can become problematic because of decreased drive, fatigue, and rigidity. • Sexual satisfaction was associated with marital satisfaction. • Predictors of quality of sexual life include male gender, better motor functioning, and quality of sexual life for partner.
	Treatment Effect	<ul style="list-style-type: none"> • Higher levodopa doses were associated with increased thoughts of breaking up. • People with PD who participated in a dance class with their spouse found it increased moral support. • The effect of DBS on the couple role is mixed.
Parent/ Family Role	Treatment/ Intervention	<ul style="list-style-type: none"> • A tango intervention improved family role functioning. • After DBS people with PD typically had improved relations with their children.
	Sharing disease/ Communication	<ul style="list-style-type: none"> • Family relationships are affected early in the disease. • Some people with PD feel the need to “protect” their families from the diagnosis. • Some people with PD feel sharing their diagnosis with their families helps them better manage.

Social Role	Sub-theme	Summary of results
	Relationship Satisfaction	<ul style="list-style-type: none"> Sometimes there is no change in family relationship quality after diagnosis. For some parenting becomes more important after diagnosis.
Friendship Role	Number of social contacts/social connectedness	<ul style="list-style-type: none"> People with PD are less likely to have many close friends. The number of friends may stay the same, but typically people with PD initiate fewer visits to friends. Some people conceal themselves from others, which disrupts social connectedness.
	Quality of Life	<ul style="list-style-type: none"> Changes in social contacts also substantially influence quality of life.
	Relationship Quality	<ul style="list-style-type: none"> Some friendships were strengthened while others lost friends because of the disease. Identification and involvement with the larger PD community was a meaningful source of friendship and support.
Work Role	Clinical/PD Symptoms/Predictors	<ul style="list-style-type: none"> Age, anxiety, fatigue, motor symptoms, apathy, cognition interfere with work performance.
	Housework	<ul style="list-style-type: none"> People with PD were less likely to participate in household management.
	Work Unavailability/Leaving the workforce	<ul style="list-style-type: none"> People with PD are less likely to work. Some people try to keep their jobs as long as they can and worry about losing social connections from work. Reasons for leaving work include being unable to meet demands. People who continue to work try to hide their symptoms and try to maintain job performance rather than working toward a promotion.
	Treatment/Intervention	<ul style="list-style-type: none"> No evidence that levodopa influences work role. Work activity often became worse after DBS.
Social and Leisure Role	Activity Type	<ul style="list-style-type: none"> More likely to engage in solitary and/or sedentary activities.
	Treatment/Intervention Effect	<ul style="list-style-type: none"> No evidence that levodopa helps with social activities. Participation in physical activities (e.g. dance class) helped with social interaction. DBS had no effect on social and leisure role.
	Clinical/PD Symptoms	<ul style="list-style-type: none"> Hoehn & Yahr stage, fatigue, mobility, and lack of symptom control were related to leisure role functioning. Some people with PD are embarrassed by symptoms which makes them pull away from activities.